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User Experiences of an Electronic Personal Health Record for Diabetes

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Original paper: User Experiences of an Electronic Personal Health Record for Diabetes

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Keywords

diabetes mellitus; eHealth; electronic health record; patient portal; questionnaires.

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Figures and Word count

2 figures, 4 tables, 3,463 words

For Peer Review

Abstract

Background

My Diabetes My Way (MDMW) is an electronic Personal Health Record (ePHR) that provides access to educational resources and clinical data to people with diabetes in Scotland. This questionnaire study aims to assess user experience, barriers to access, and inform future development.

Methods

All active MDMW users (n=3,797) were invited to complete an online questionnaire in May 2015, surveying usage patterns and system utility. A “utility score” was calculated, based on responses to Likert-scale questions and used as the dependent variable within regression analysis, with demographic features as independent predictors. Free-text responses were analysed thematically and presented using descriptive statistics.

Results

1,095/3,797 (27.5%) active users completed the survey. 690/1,095 (63%) were male. There was representation of all age and socioeconomic groups. Respondents were positive regarding the system utility, which met expectations. The majority of respondents believed that online access to diabetes information has the potential to improve diabetes self-care within the population. The most valued features were personal clinical data associated visualisations. The main problems cited were data accuracy and system access (i.e. log in procedure). Perceived usefulness of the system was inversely associated with duration of diabetes, which was the only significant predictor of utility score.

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Conclusions

This study has demonstrated that MDMW users find the system useful in supporting diabetes self-management. The system was found to have greatest utility amongst those most recently diagnosed with diabetes. This study has informed further development of the service, including enhancing data visualisation and the need to improve access to the system.

For Peer Review

Introduction

My Diabetes My Way (MDMW)[1] is the NHS Scotland interactive website for people with diabetes and their carers. It contains a variety of multimedia resources aimed at improving self-management, including: traditional information leaflets, interactive educational tools, and videos describing complications.

MDMW was launched in 2008, initially as an open access website containing the above resources. From 2010, MDMW has offered its users access to their clinical data via its novel electronic personal health record (ePHR). The service was initially developed by the University of Dundee but is now available to all people with diabetes in Scotland (approximately 300,000 [2]). By the end of 2015, there were nearly 17,000 registered users (6% of people with diabetes in Scotland), distributed evenly throughout all NHS boards in Scotland [3]. Use of MDMW is associated with improved glycaemic control and other clinical outcomes [4]

In order to enrol, a patient must verify their email address and consent to their data being made available to them online. This ePHR links to SCI-Diabetes, NHS Scotland's flagship diabetes record [5]. This system includes data from primary and secondary care, specialist screening systems (retinopathy screening, podiatry, etc) and laboratories. These data include diagnostic information, demographics, process outcomes, screening results, medication and clinical correspondence. The system provides a more complete overview of diabetes than would be available from any single data source, such as an isolated primary care or hospital clinic database.

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The MDMW ePHR takes a subset of data from SCI-Diabetes, focusing on key diabetes indicators, such as HbA1c, blood pressure, body mass index, etc. Alongside these data is descriptive text explaining each assessment, detailing why they are recorded and what normal range values are. Further educational materials are presented alongside clinical results and are tailored to those using the service. For example, foot care advice is based on the patient’s recorded foot risk assessment category. History graphs and tables allow individuals to track changes over time for the full duration of their clinical record from multiple electronic data sources. MDMW aims to provide highly tailored information and provides advice based on the Diabetes UK “15 Healthcare Essentials” campaign [6]. Patients can also manually enter home-recorded information (weight, blood pressure, etc), or automatically upload blood glucose results. Users receive a monthly MDMW newsletter via email. In addition, users who have not logged in to MDMW for 6 months are contacted directly to assist them in accessing their account.

This study aims to assess users’ experience of MDMW, with regards to perceived benefits and shortcomings. In particular, we aimed to characterise users’ attitudes to accessing their ePHR via online means, assess whether the service is meeting user expectations, and survey users to inform desired future developments of the system.

Methods

A 35-item questionnaire was devised and written in an electronic format for completion online. The questionnaire aimed to gather feedback on 3 main areas, presented on separate pages: the registration process and usage patterns (6 items), the utility of the system (17 Likert-scale items plus one free text item), and support services for the system (5 items). Finally, the questionnaire offered free text responses to allow users

to identify the best parts of the system, the worst parts, and desirable features that are not currently available. The questionnaire was developed by principal investigator, in conjunction with the MDMW steering group (consisting of lay and health professional members) and was previously piloted amongst MDMW users.

An invite was emailed to all active, registered MDMW users (convenience sample, n=3,797) in May 2015. Active users were defined as those that logged in to the system at any point following the registration process. The invite email contained a link to the questionnaire that was live to respondents for a period of 1 month from the date of invite. Survey completion was completely voluntary, with no impact on access to the MDMW site and no incentives to complete. No reminder emails were sent. The survey was hosted by a proprietary company (SurveyMonkey [7]), using a generic template. All questionnaire items were voluntary, with no completeness check or other forms of data validation. Respondents could amend responses to all items prior to final submission. The URL to access the questionnaire contained a de-identified “key”, restricting respondents to a single response and ensuring that the survey was closed to those without the invite email. This “key” also allowed responses to be retrospectively matched to user account details. Demographic variables were then extracted from the MDMW system, thereby removing the need for respondents to provide personal identifiers or information.

Likert-scale responses for system utility were summed and divided by the maximum possible value to provide a “utility score” out of 1 (0 = low utility, 1 = high utility). The utility score was used as the dependent variable within a regression analysis (see below). Likert responses were also collapsed into “agree”, “neutral” and “disagree”

categories, for the purposes of graphical representation. Free text responses were thematically analysed by the lead author and coded by theme, thereby enabling descriptive statistics to be calculated. The denominator used to calculate percentages varied according to the number of responses for each item. For free text responses, responses often contained more than one theme, in which case this was coded to allow aggregates to be calculated appropriately.

Demographic variables were available for all active users and included age, ethnicity, sex, diabetes type and duration, and socioeconomic status (SES). SES was derived from the Scottish Index of Multiple Deprivation (SIMD), obtained from home postcode and expressed in quintiles ranging from most deprived to least deprived [8]. Respondents' SES was compared with non-respondents, as was the system usage in the year prior to the questionnaire invite. Multivariable regression analysis was used to identify groups of respondents which felt that the system has greatest utility. Demographic groups were compared using Mann Whitney U test. Regression was also used to explore demographic predictors of system usage

This project was a service improvement project, therefore was not subject to medical research ethics review. All invites to complete the questionnaire were sent to MDMW users who previously consented to receive unsolicited email from the MDMW team (consent obtained at initial enrolment).

Results

1,095/3,797 (27.5%) active users completed the survey.

690/1,095 (63%) were male. 789/1,095 (72%) had T2D, 290/1,095 (27%) had T1D, with the remainder having other types of diabetes. Age was normally distributed around the

mean of 58 years (SD 12, range 18-88). There was a representation from all socioeconomic groups, however there were a greater number of respondents from the least deprived categories. There was no significant difference in SES between respondents and non-respondents - (see Figure 1).

The vast majority of respondents (873/1,095, 80%) identified as “White” (British, Irish or Scottish). 80/1,055 (7%) were in other minority groups, with the remainder being unknown. Duration of diabetes ranged from 1 month to 61 years and was skewed towards those more recently diagnosed (median duration 91 months, interquartile range 155). Those with T2D had had diabetes for significantly less time than those with T1D (median months (IQR): 69 (118) versus 224 (307), $p < 0.001$). Those with T2D were also significantly older (years (SD): 61(10) versus 50(13), $p < 0.001$).

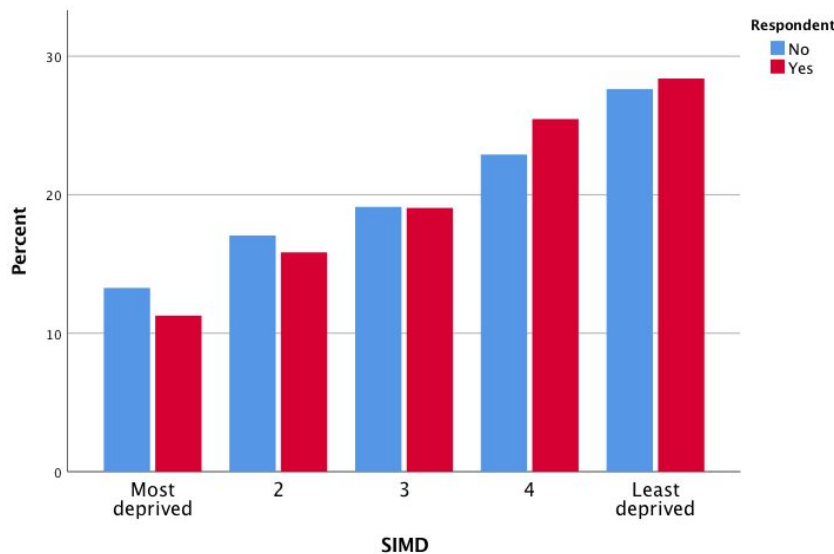


Figure 1. Scottish Index of Multiple Deprivation (SIMD) quintiles for all MDMW users invited to complete the survey. Percentages calculated for each legend category.

Approximately a third of users became aware of MDMW via publicity material at the hospital clinic 358/1095 (33%), a third via material at the GP surgery (324/1095 (30%).

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The majority of the remainder became aware of MDMW via online means (206/1095, 18.8%). Most users access the system from home (876/966, 80%), during the evening or night (611/946, 55%), with no set day on which they do so (938/968, 86%). In the year prior to completing the questionnaire, respondents accessed the system significantly more than non-respondents (median number of log ins (IQR): 5 (8) versus 1 (4), $p<0.001$). Those with Type 2 diabetes accessed the system significantly more than those with Type 1 diabetes (median log ins (IQR): 5 (9) versus 4 (6), $p=0.001$). There were no other significant demographic predictors of system usage, including SES.

Respondents' agreement to a variety of statements is provided in Figure 2. The statement that elicited the most agreement with users related to the usefulness of the graphs (818/989, 83% agree that they were helpful, 348/989 (35%) of whom were in strong agreement). A similar number of users were confident in the security of the data within the system (799/990 (81%), 316/990 (34%) of whom were in strong agreement with the statement regarding confidence in data security). A sizable majority were also of the belief that MDMW has the potential to significantly improve diabetes self-care within the population (803/985, 82%), with 331/985 (34%) in strong agreement.

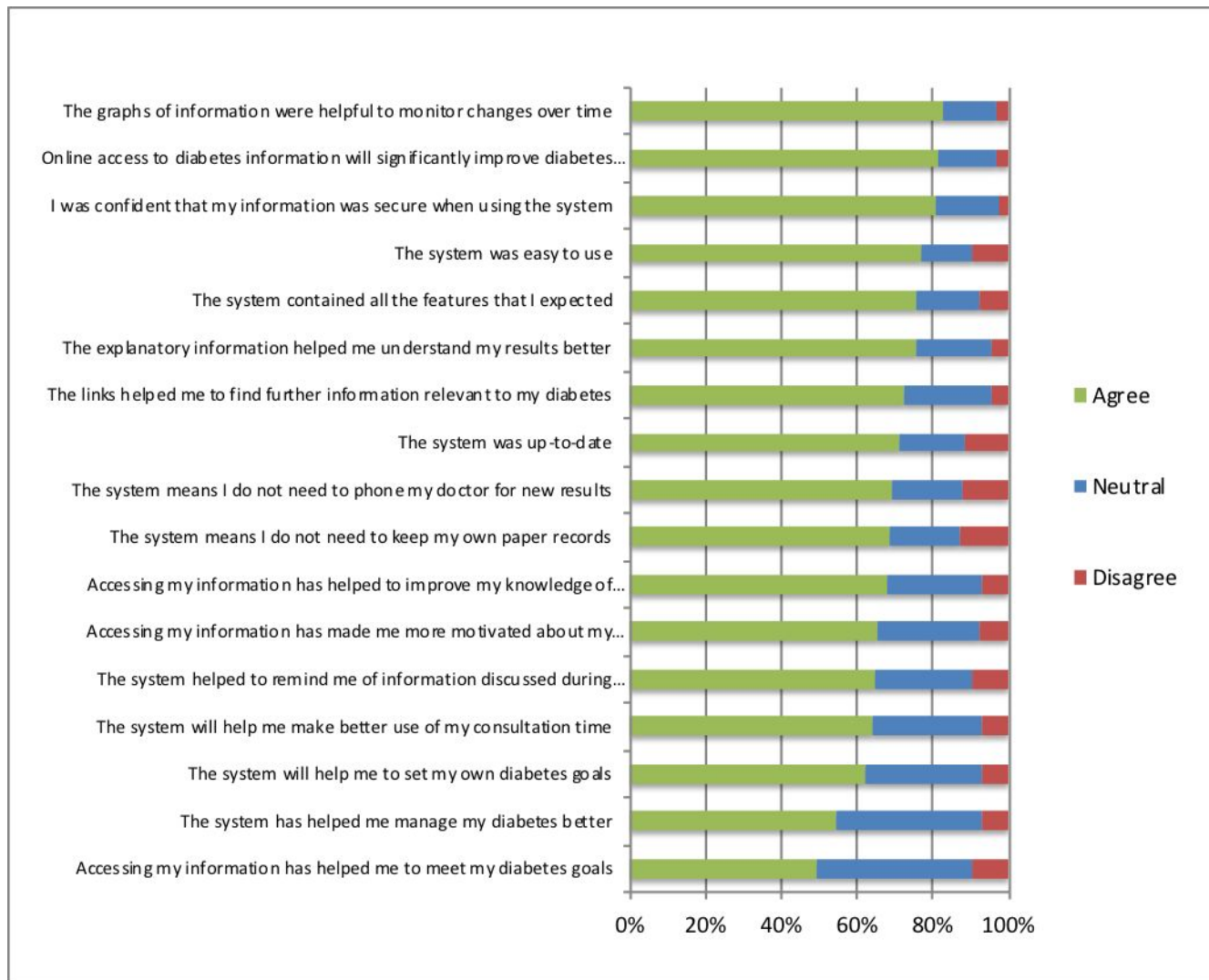


Figure 2. Collapsed responses to statements regarding system utility (n=985-997), listed by decreasing order of agreement.

Of the 1,095 respondents, 916 (84%) answered all 17 items relating to system utility, thereby allowing a utility score to be calculated. The utility score was skewed towards higher scores, with a median of 0.78 (interquartile range 0.14). Utility score was inversely associated with duration of diabetes, which was a highly significant predictor ($p < 0.001$). Both duration of diabetes and type of diabetes were significant univariable predictors of utility score, however type of diabetes was not significant when entered simultaneously with duration – Table 1. Socio-economic status was not predictive of utility score, although there was a (non-significant) trend for lower utility scores within

the less deprived groups. System usage in the year prior to completing the questionnaire did not predict utility score.

Table 1. Univariable and multivariable predictors of MDMW utility score. Univariable predictors significant to $p<0.1$ entered into multivariable model. SIMD = Scottish index of multiple deprivation. “White-British” includes all who identify as “White – British”, “White-Irish” and “White-Scottish”.

		Univariable			Multivariable		
		B	95% CI	P	B	95% CI	P
Diabetes type	T1D versus T2D	-0.041	-0.059 to -0.022	<0.001	-1.374	-3.57 to 0.821	0.220
	Other diabetes types versus T2D	0.02	-0.052 to 0.092	0.587	0.588	-6.85 to 8.03	0.877
Duration	Years since diagnosis	-0.002	-0.003 to -0.001	<0.001	-0.002	-0.003 to -0.001	<0.001
Age	Years	0.0003	-0.0004 to 0.0010	0.420	-	-	-
Socio-economic status. (Compared with most deprived quintile)	SIMD 2nd quintile	0.003	-0.029 to 0.035	0.847	-	-	-
	SIMD 3rd quintile	-0.004	-0.035 to 0.027	0.785	-	-	-
	SIMD 4th quintile	-0.005	-0.034 to 0.025	0.754	-	-	-
	SIMD 5th quintile (least deprived)	-0.016	-0.045 to 0.013	0.279	-	-	-
Gender	Male versus female	-0.004	-0.021 to 0.014	0.678	-	-	-
Ethnicity	All other ethnicity groups versus white - British	-0.021	-0.052 to 0.011	0.204	-	-	-
	Ethnicity not known versus white - British	0.02	-0.005 to 0.046	0.113	-	-	-
System usage	Number of log ins in preceding year	0.034	-0.008 to 0.076	0.114			

In response to the question “What was the best part of the system and why?”, 614/1095 (56%) provided a response. There were 7 key themes identified, in addition to other comments that were uncategorizable. The most commonly cited feature was being able access to the complete medical record (302/614, 49%) i.e. ability to view their complete diabetes record, including biochemical data, results of screening investigations, and clinical correspondence – see Table 2.

Table 2. Free text responses to “What was the best part of the system and why?”. Free text coded by theme and key themes presented in order of decreasing prevalence (n=614).

Theme	Example quote
Provides a complete health record	“Not having to chase Dr's for results”
Data visualisation	“Love the Graphs. Useful to see if there have been changes.”
Insight into longitudinal trends	“Graph on sugar levels over time”
Understanding of condition	“Very useful information about diabetes, treatments and lifestyle... It helps with the discussion about future treatments to prevent complications.”
24/7 access to records	“Having all my information to hand and being able to access it when it suits me. Helps me feel in control and reduces the sense of diabetes controlling me.”
Normative reference ranges for clinical parameters	“made it easy to see exactly where I stood regarding my results using the tragic ligh [sic] colours system”
Record of medication used	“I am changing the dosage of metformin and this helps keep track of things.”

Respondents also valued the various data visualisation tools (e.g. line graphs, target charts etc.), thereby allowing increased insights into how to interpret personal data, track progress through time, and compare their values against normative reference ranges. Users valued how the system afforded insights into their underlying condition and the how their data trends through time. They valued being able to access the system at any time and also being able to view an up to date record of their medication.

In response to the question “What was the worst part of the system and why?”, approximately one third (347/1095 (31%)) provided a free text response. The responses were grouped into 7 key themes – see Table 3.

Table 3. Free text responses to “What was the worst part of the system and why?”. Free text coded by theme and key themes presented in order of decreasing prevalence (n=347).

Theme	Example quote
Accessing the system	“The initial setting up was complicated with a difficult to remember login in name etc”
Incomplete dataset	“No access to hospital letters”
Format of information provided	“All online info is too wordy!”
Inaccuracies in data provided	“Blood results and weight taken st [sic] surgery not up to date”
User interface	“The entire website is really hard to navigate.”
Data entry	“Entering several blood sugar results is slow and tedious”
Unable to contact administrators	“Making contact when I had an issue with my password.”

By far the most common complaint was with difficulty accessing the system (i.e. the initial log in process), cited by just under half of respondents (154/347 (44%)). Problems with data were the next most common complaint, including lack of accuracy, missing data and problems with entering data onto the system. The user interface was criticised for being “clunky” and providing information in a format that was, at times, confusing. Lastly, users experienced frustration in getting help when contacting the system administrators in order to report problems. Only three individuals (1%) cited data security as being a concern.

In response to the question “What new features would you like to see added to the system?”, 253/1095 (23%) individuals responded with free text suggestions. These responses could be grouped into 8 main categories, which to some extent provided possible solutions to the previously identified problems – see Table 4.

Table 4. Free text response to “What new features would you like to see added to the system?”. Free text coded by theme and key themes presented in order of decreasing prevalence (n=253).

Theme	Example quote
Additional resources	“A conversion feature for the HbA1C - from the old percentage way we used to do it to the new number way”
Data upload/download	“Some interface between blood meter and home recordings to automate the process”
Diary of events	“NHS system automatically putting appointments on my account and then giving me email reminders of when they're due.”
Improved access	“Making the system easier to log onto”
User support	“A faster response time to my queries.”
User interface	“Better layout, pages tend to be very busy.”
App version	“It would be nice to have some sort of mobile integration - maybe an app where you can easily enter your meals and insulin doses on the go.”

The most desired feature suggested by respondents was additional educational resources (112/253, 44%). Users expressed a desire to upload and download data more readily and that these data were visualised in a more intuitive way, with the use of data validation to avoid data transcription error. Improving ease of access to the system as well as customer support to do so were identified as priorities. An improved user interface as well as a mobile app version were also suggested, which should contain a more user-friendly diary of events. One person suggested the introduction of “gamification” (i.e. the use of incentives and competitive features, derived from the video game industry [9]), by way of motivating users.

Discussion

Principal results

This study has demonstrated that this cohort of MDMW users are generally satisfied with the system and value features such as access to their medical data and data visualisations. Duration of diabetes was inversely associated with perceived usefulness. Interestingly, perceived usefulness was not related to age, gender or socioeconomic status, nor was it related to prior system usage. User feedback would suggest that improvements can be made with regards to registering with and accessing the system as well as providing additional resources in an accessible way.

Comparison with prior work

MDMW is a useful aid to diabetes self-management, providing access to people with diabetes in Scotland. It is unique in offering access to a complete geographical population, providing information from many diabetes-related sources. MDMW supports the diabetes improvement, self-management, healthcare quality and eHealth strategies of the Scottish Government.

This study has demonstrated that overall user satisfaction with the MDMW system is high, and that the majority of users feel that the system is a useful adjunct to diabetes self-care. Web-based interventions for those with diabetes have been shown to improve clinical outcomes [10]. Recent analysis of clinical outcomes amongst a large population of MDMW users has demonstrated improved glycaemic control [4]. At a population level, small improvements in glycaemic control are associated with considerable long-term savings due to a reduction in diabetes-related complications [11].

Electronic health applications are often developed in isolation and may not reflect the user requirements of the population that they are designed for [12]. The questionnaire has identified areas for improvement and has directly informed development of the website. In particular, the registration process has since been simplified, resulting in improved access to the system, the user interface is being improved and a MDMW app has been developed. Work is also being done to enhance electronic communications and improve data uploading (including data from smartphone apps and wearable sensors) as well as developing patient-specific decision support. This study has identified areas for further improvement, including the availability and accuracy of data, although it should be noted that these problems were only voiced by a minority of users. Users expressed a desire for additional data feeds from other specialties. In Scotland, the diabetes digital landscape is relatively mature when compared to other specialties. The MDMW system architecture allows it to link with other electronic clinical records via its standardised generic interface, thereby allowing such data feeds to be developed in future.

Internet usage patterns can reflect underlying demographic and socioeconomic differences, with the potential to increase health inequalities [13]. For example, those with lower health literacy are less likely to access an ePHR [14]. In this study, no particular sociodemographic sub-group found MDMW to be more or less useful. However, the limitations of the study make it difficult to generalise these findings to the wider population (see below). It is notable that the utility of the site was inversely related to duration of diabetes amongst the respondents – the reasons for this remain speculative at this stage and should be explored in future studies.

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3 Limitations
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5 The response rate to the questionnaire was low, but is in keeping with other electronic
6 surveys [15]. There was a higher proportion of respondents from less deprived areas,
7 raising the possibility of sampling bias - the prevalence of T2D tends to be higher in
8 more deprived areas, whereas T1D does not follow a deprivation gradient [16].
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10 However, there was no significant difference in respondents' SES compared with
11 MDMW users that did not respond, suggesting that this sample reflects MDMW users in
12 general. Whilst MDMW users tend to be from less deprived areas, prior system usage
13 was not predicted by SES status.
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17 The proportion of respondents with T1D was higher than the general population [2],
18 but is in keeping with other users of MDMW. There was limited diversity in the
19 ethnicity of respondents, however this reflects the Scottish diabetes population [2].
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21 Similarly, age distribution and gender balance was similar to the wider population [2].
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25 Conclusion
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27 MDMW is an innovative and unique ePHR that is associated with improved clinical
28 outcomes. This study has demonstrated that the system is a useful addition to diabetes
29 management in this sample of MDMW users. In addition, this study has identified
30 areas for improvement which has informed subsequent development. These findings
31 have relevance beyond the immediate MDMW platform and can guide developers of
32 other systems to ensure patient satisfaction. The MDMW user-base continues to grow
33 significantly with >39, 000 registered users and >19,000 active users (May 2018),
34 ensuring that future attempts at gaining user feedback will benefit from representation
35 of a broad cross-section of the diabetes community.
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A spin out company (MyWay Digital Health Ltd) has been created to develop and commercialise MDMW for other markets.

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Conflicts of interests

SGC and DJW are directors of MyWay Digital Health Ltd.

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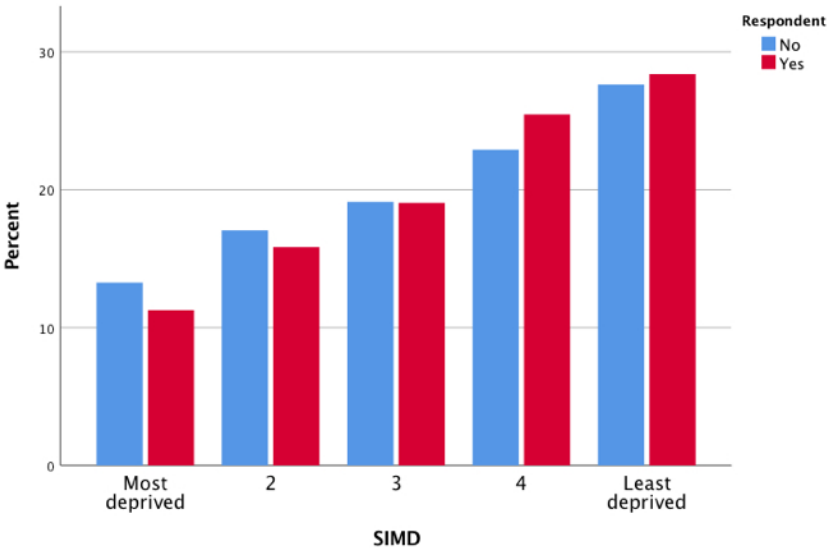
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Abbreviations

CI	Confidence interval
ePHR	electronic personal health record
GP	General practitioner
HbA1c,	Haemoglobin A1c
IQR,	Interquartile range
MDMW	My Diabetes My Way,
NHS	National Health Service
SCI-DC	Scottish Care Information - Diabetes Collaboration
SIMD	Scottish Index of Multiple Deprivation
T1D	Type 1 diabetes
T2D	Type 2 diabetes
UK	United Kingdom



Scottish Index of Multiple Deprivation (SIMD) quintiles for all MDMW users invited to complete the survey. Percentages calculated for each legend category.

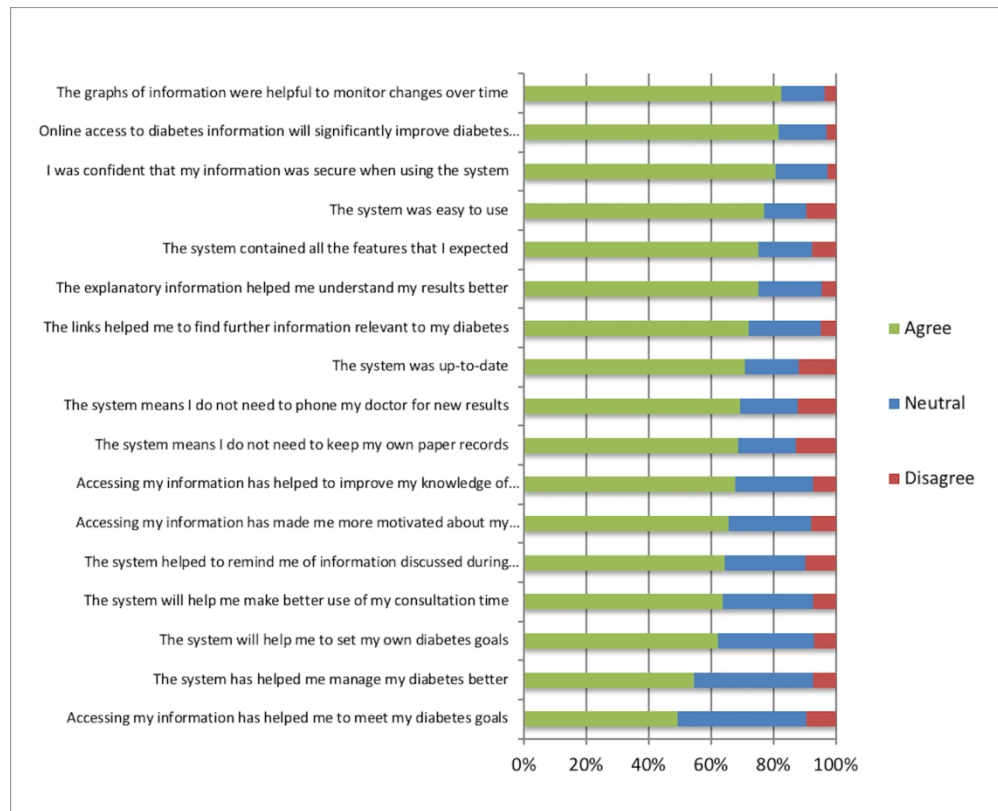


Figure 2. Collapsed responses to statements regarding system utility (n=985-997), listed by decreasing order of agreement.